

## **Developing an Early Life Parent Education Programme in response to High Infant Mortality Rates**

### **Authors:**

Dr Thillagavathie Pillay  
MBChB, DCh, FCPaed, MD, PhD, FRCPCH  
Neonatal Unit  
Royal Wolverhampton NHS Trust  
Tilly.pillay@nhs.net

Ms Kerry Porter  
Support Worker  
Neonatal Unit  
Royal Wolverhampton NHS Trust  
Kerry.porter3@nhs.net

Ms Sarah Marson  
Support Worker  
Neonatal Unit  
Royal Wolverhampton NHS Trust  
Sarah.marson@nhs.net

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## **Letter to the Editor:**

### **Developing an Early Life Parent Education Programme in response to High Infant Mortality Rates**

In 2012, Public Health England reported infant mortality in Wolverhampton, a socially disadvantaged region, as amongst the highest in the country[1]. Prematurity, congenital anomalies and sudden Infant death were identified as leading causes, with risk factors smoking, low birth weight, maternal age, late booking, ethnicity and social deprivation[2].

The potential benefit of a parent education and support programme[3], to raise awareness around common factors associated with infant mortality in the region, and support parents with up to date information on how to minimise these risks for their babies was noted. No such programme existed previously in the region. The neonatal unit in Wolverhampton launched a programme in January 2016[4], and describe the establishment, uptake and parents'/carers' experience.

*The programme:* We channelled available resources into a central education programme, called STORK (Supportive Training, Reassurance and Knowledge). This included 1:1 training to parents/carers whose babies were receiving care at the neonatal unit at New Cross Hospital, Royal Wolverhampton NHS Trust and comprised a) training on managing infant choking and resuscitation, b) advice aimed at reducing the risk of SIDS[5], c) how to identify the ill baby d) advice on smoke free homes/environment, and referral to the Trust's smoking cessation teams, e) support for breast feeding and other feeding choices being offered by breast feeding midwives, neonatal nurses, community nurses and health visitors, and f) guidance on healthy weaning and healthy eating with referral to healthy lifestyles teams at the hospital where appropriate. This programme included pre-discharge information sharing (talks, leaflets, DVD), skills drills, and question and answer sessions eg: spot the five things wrong in this photograph.

Prior to commencement of the programme, two support workers underwent a two week intensive 'training the trainer' programme supervised by the senior consultant neonatologist. The STORK team comprised these workers, with input from the Trust's smoking cessation and Healthy lifestyles teams, and breast feeding neonatal nurse programme. Specific training on sudden infant death prevention was undertaken through the Lullaby Trust[5].

This programme was offered to parents/carers whose babies were admitted to the neonatal unit at New Cross Hospital. The long term intent is to expand it to all expectant mothers in the region. Parents or carers who were willing and able to give informed consent and participate were included. Participation was voluntary. Where parents did not have English as their first language the information shared was augmented by available parent information leaflets in their mother tongue. The Trust Governance group approved the project design and content. We report on the first six months of feedback from the parents/carers.

*Results:* 218 parents/carers were approached; uptake was 100%. 12 parents had multiple pregnancies. Maternal age ranged from 15-47(median 28) years and 35.8% represented ethnic

minority groups. The gestational age range of their babies was 25-40 weeks. Babies stayed in hospital (neonatal unit, transitional care or post natal ward) for a median of 2(range 0-84 days; with longer durations of stay in the more premature babies. In 207(95%) parent/carer training episodes, mothers were accompanied by their partners; in 6 cases, grandparents attended as well.

Three mothers had had a previous child with sudden infant death syndrome. Babies of 2 mothers who participated in the programme had died: one, a sick preterm twin who died before mother received the education package (for the surviving twin), and the other, a preterm singleton, who died after mother and father had received the education package. 129 (59%) parents engaged with the STORK nurses for further nursing and emotional support after they had received STORK training but before discharge from hospital.

24 parents or carers admitted to smoking in pregnancy (11%); of these, 10 (41.7%) accepted a referral to the smoking cessation team. A further 14 (6%) accepted referral to the healthy lifestyles team for advice on healthy eating and weaning for their child.

215 (98.6%) of 218 parents or carers provided feedback that the programme was useful, that they would recommend it to others and that it instilled confidence in them caring for their babies after discharge from the neonatal unit. The remaining 3 did not answer and English was not their first language. Table 1 details free text responses from parents and carers.

*Discussion:* This programme provides essential information, and empowers parents/carers as service users in not only dealing with potentially life threatening situations, but also in thinking about lifestyle changes based on knowledge of associations and risks. Such a package is unlikely on its own make an impact on outcomes without a continuum of education/support across all ages. Its value is perhaps as a tool for engagement with the community, investing in parents, and optimising their understanding and care for their newly born baby and infant.

Although 20-25% of women smoke in pregnancy in the Wolverhampton region[1], 11% declared this. It is encouraging to see that nearly half accepted referral to smoking cessation teams in the Trust. The longer term aims will be to evaluate how better to engage more parents, carers and family members in the smoking cessation programme, and to evaluate the success of referrals in fostering smoking cessation. Obesity is an increasing health issue in the region[1]. It is encouraging that families engaged with health teams in seeking advice regarding healthy weaning for their infants.

That a third of all parents and carers supported were of ethnic minority suggests that a complete roll out programme is likely to get widespread engagement, enabling it to reach target population groups. Parents appreciated the additional support on feeding techniques offered by the team, and breast feeding rates on discharge and up to 3 months of age will be captured in the continuation phase of this project.

The immediate positive impact of the programme is evident in parent perceptions suggesting greater confidence in caring for their babies. This programme appears to have the potential for sustainability. Our long term objective will be to embed it into the community, with community

based guardians (parent support groups) playing a pivotal role in providing support for families with a new born baby.

Table 1: Selected Parent Feedback Comments for parent/carer STORK training on the Neonatal Unit

Very informative and should be offered to all parents
I think this should be available to all parents. Found it really useful even after having 3 babies
All parents should be offered this!
It's a great programme and all parents will benefit from it. I know I have!
Really useful –should be available to all parents
Really appreciate eagerness of staff to come and help us
Include grandparents/relatives; Make it compulsory for first time parents
Make nursing staff more aware for STORK referrals
I can truly say this service has made me feel 100% confident in taking my baby home! Couldn't be more grateful. Thank you!
Very useful and helpful instructor. Wish all mums had this opportunity.
Really helpful. Get to know things you didn't before and understand it better
It's good to help save babies life. Every parent should do
Very informative, thank you
This made me feel at ease about taking my baby Harry home knowing about the ways to safe sleep. Brilliant today. Thank you very much!
Very good. Helped put my mind at ease should the need arise. Felt very comfortable
Trainer very informative and helpful; Additional advice given on other topics; Reassurance given
Covered a lot I wasn't even aware of
Was very useful and has made me aware now as I didn't have a clue about any
Absolutely I think all parents should go through this not just ones on neonates unit
Excellent trainer. Very informative
Found this very useful as without it we would not of known of any of the information covered especially the bits on sleeping and the first aid
Really informative should be made available to all moms!
This is a really good service
Very well taught!
the trainer is very good and emphasises the importance of safe sleep but does it in a friendly and caring way
Very useful friendly and supportive staff
Great programme! Answers the questions I didn't even think of. Would recommend it antenatally. Every parent should have this programme at some point pre/post natal
This is a good and educative programme and I think it should be extended into the community to aid new mums
It was very useful and worthwhile. Thank you!
Glad of the advice. Helped to ease our own concerns
Really useful and we learnt a lot of what we didn't know
Told me a few things I was not aware about
Very helpful to me
Should be made compulsory for families
We found the programme very useful and helpful
Was brilliant!!

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